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Impact of Multiple Sclerosis on Quality of Patient's Life

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ABSTRACT

Background: Multiple sclerosis (MS) is a chronic autoimmune neurological illness that has a significant influence on an individual's, families, and society's health-related quality of life. We aim to identify the burden of Multiple Sclerosis and its impact on patient's quality of life.

Methods: This study was a cross-sectional study, carried out in the Neurology Department, Zagazig University Hospitals and Al-Mabara Medical Insurance Hospital, Zagazig. The study was carried out from January 2020 to December 2020 on 60 MS patients diagnosed according to the Revised McDonald criteria. Detailed history was taken from all participants. Complete general and neurological examinations were performed. Disability was assessed using Kurtzke Expanded Disability Status Score (EDSS). Cognitive function was assessed using the Arabic version of the Montreal cognitive assessment (MoCA) scale. A self-related Health Status Questionnaire was implemented. Work performance related to physical, cognitive, and psychological dimensions was studied with the 23-item Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ-23).

Results: MS patients with more disability (EDSS more than 3.5) have statistically significant cognitive impairment according to MoCA score ($P = 0.001$) and have also high statistically significant increase in workplace problems according to MSWDQ-23 score than those with EDSS less than 3.5 ($p < 0.001$). **Conclusions:** There is a substantial impact of MS on patients' QOL, owing to the patients' psychological and physical conditions, as well as the unfavorable influence on work conditions.

Keywords: Sclerosis; EDSS; MoCA; Neurology.



INTRODUCTION

Multiple sclerosis (MS) is a chronic autoimmune neurological illness that has a significant influence on individuals, families, and society's health-related quality of life. Multiple sclerosis is most commonly diagnosed in young, energetic adults aged 20 to 40. With an estimated 59,671 MS patient, Egypt has the biggest number of MS patients in the Middle East area, with a significant burden due to delays in diagnosis and treatment beginning, as well as financial hardship [1]. The majority of MS patients have severe symptoms that lead to a variety of impairments and a disrupted life rhythm, impairing their quality of

life and ability to do everyday activities. Due to their medical issues, many MS sufferers have expressed pessimism, unemployment, and retirement [2].

Even in a population with modest physical impairment, multiple sclerosis (MS) causes significant economic burden due to indirect and informal care expenditures. Patients with MS will also require caring as their disabilities worsen, which will be given mostly by informal careers such as spouses or other relatives [3].

METHODS

This study was a cross-sectional study, carried out in the neurology department, Zagazig University

Hospitals and Al-Mabara Medical Insurance Hospital, Zagazig. The study was carried out from January 2020 to December 2020 on 60 MS patients diagnosed according to the Revised McDonald criteria. Patients not fulfilling McDonald criteria for diagnosis of MS or MS patients with other neurological diseases, serious cardiovascular or other disability precluding participation were excluded from the study. Detailed history was taken from all participants including (onset and duration of illness, number of relapses, number of admissions to hospital and type of treatment). Complete general and neurological examinations were performed. Disability was assessed using Kurtzke Expanded Disability Status Score (EDSS). Cognitive function was assessed using the Arabic version of the Montreal cognitive assessment (MoCA) scale. A self-related Health Status Questionnaire [Short Form 36 (SF-36); 36 items, Arabic version] was implemented. Work performance related to physical, cognitive, and psychological dimensions was studied with the 23-item Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ-23).

Written informed consent was obtained from the patients or their parents after clear explanation of the study and the study was approved by the research ethical committee of Faculty of Medicine, Zagazig University (Institutional Research Board "IRB"). The work has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for studies involving humans.

Statistical analysis:

Data were fed to the computer and analyzed using IBM SPSS software package version 20.0. (Armonk, NY: IBM Corp). Qualitative data were described using number and percent. The Kolmogorov-Smirnov test was used to verify the normality of distribution. Quantitative data were described using range (minimum and maximum), mean, standard deviation, median and interquartile range (IQR). In the independent samples, Independent -t test was used to compare two groups of normally distributed data while, Mann Whitney MW test was used for non-normally distributed data. Significance of the obtained results was judged at the 5% level.

RESULTS

Table (1) shows that among the studied cases there were 18 (30%) males and 42 (70%) females with mean age 32.8 ± 7.49 and range of (17-51) years. 85 % of them were married. There were 50% employed and 38.3% housewives, 6.7% students and 5% retired. According to the course of the disease in our MS patients, 49 (81.7%) patients had RRMS, 6 (10%) patients had PPMS, and 5 (8.3%) patients had SPMS. Among those patients there were 38 (63.3%) patients with level of education more than 12 years and 22 (36.6%) patients had equal or less than 12 years of education. Table (2) clears that the mean duration of illness of MS patients was 5.17 ± 3.91 years. The mean number of relapses was 3.40 ± 1.58 . The mean duration from last attacks was 16.8 ± 8.9 months. The mean number of admissions to hospital was 2.55 ± 1.41 . Table (3) reveals the descriptive analysis of the clinical scales for MS patients. The mean EDSS for our MS patients was 3.14 ± 1.92 with range (1-8). Their mean MoCA scale score was 26.92 ± 1.28 with range (23-29). Their mean MSWDQ score was 28.81 ± 17.96 with range (8.7-68.3). Table (4) demonstrates that MS patients with more disability (EDSS more than 3.5) have statistically significant cognitive impairment according to MoCA score ($P = 0.001$) and have also high statistically significant increase in workplace problems according to MSWDQ-23 score than those with EDSS less than 3.5 ($p < 0.001$). The relation between the age at onset of MS illness and different MS quality of life assessment scores was demonstrated in Table (5). In group of patients with age at onset ≥ 25 years old, there was a highly statistically significant increase in workplace problems according to MSWDQ-23 with mean (33.68 ± 18.29) ($p < 0.001$), and a highly statistical disability according EDSS (3.60 ± 2.02) ($p = 0.004$). Table (6) shows that according to the number of MS relapses, patients' group with more than three relapses had a statistically significant increase in cognitive affection according to MoCA score. Also, they had a high statistically significant increase in disability and workplace problems according to EDSS score and MSWDQ-23 score. Table (7) clears that there was a high statistically significant increase in disability and workplace problems in patients with disease duration equal or more than five years according to EDSS score and MSWDQ-23 score respectively.

Table (1): Demographic data of the patients.

Demographic data of patient	No.	%
Gender		
Male	18	30.0
Female	42	70.0
Age (years)		
Range.	17.0 – 51.0	
Mean ± SD.	32.80 ± 7.49	
Median (IQR)	32.0 (28.50–39.0)	
Marital state		
Married	51	85.0
Single	9	15.0
Employment status		
Employed	30	50.0
Housewife	23	38.3
Student	4	6.7
Retired	3	5.0
Course of MS		
RRMS	49	81.7
PPMS	6	10.0
SPMS	5	8.3
Level of education		
≤12y	22	36.7
>12y	38	63.3

Categorical data were presented as number and percentages. Quantitative data were expressed as mean ± standard deviation, median and range.

Table (2): Clinical characteristic of MS patients (n=60).

Disease characteristic of MS	No.	%
Duration of illness(years)		
<5 y	34	56.7
≥5y	26	43.3
Range.	0.17 – 19.0 (2 m – 19 y)	
Mean ± SD.	5.17 ± 3.91	
Median (IQR)	4.0 (3.0–6.0)	
Number of relapses		
≤3	38	63.3
>3	22	36.7
Range.	1.0 – 8.0	
Mean ± SD.	3.40 ± 1.58	
Median (IQR)	3.0 (2.0–4.0)	
Duration from last attacks (months)		
Range.	2.0 – 42.0	
Mean ± SD.	16.8 ± 8.9	
Median (IQR)	19.0 (15.0–25.0)	
Number of admissions to hospital		
Range.	0.0 – 7.0	
Mean ± SD.	2.55 ± 1.41	
Median (IQR)	2.0 (2.0 – 3.50)	

Categorical data were presented as number and percentages. Quantitative data were expressed as mean ± standard deviation, median and range.

Table (3): Descriptive analysis of the clinical scales for MS patients.

Clinical characteristic of MS	Range.	Mean ± SD.	Median (IQR)
The Expanded Disability Status Scale (EDSS)	1.0 – 8.0	3.14 ± 1.92	2.50 (1.50–4.25)
The Montreal Cognitive Assessment (MoCA)	23.0 – 29.0	26.92 ± 1.28	27.0 (26.0–28.0)
The Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ-23)	8.70 – 68.30	28.81 ± 17.96	22.40(16.25–39.15)

Quantitative data were expressed as mean ± standard deviation, median and range.

Table (4): Relation between MS disability measured by EDSS and Quality of life assessment scales (n=60).

MS quality of life assessment scores	EDSS		Test sig.	of P
	≤3.5 (n=45)	>3.5 (n=15)		
MoCA				
Range.	23.0 – 29.0	23.0 – 27.0	t=3.495*	0.001*
Mean ± SD.	27.22 ± 1.17	26.0 ± 1.20		
MSWDQ-23				
Range.	8.70 – 42.50	35.80 – 68.30	U=1.000*	<0.001*
Median	17.40	59.20		

t: Student t-test

U: Mann Whitney test

p: p value for comparing between the two categories

*: Statistically significant at $p \leq 0.05$

Table (5): Relation between the age at onset of MS illness and different MS quality of life assessment scores (n=60).

MS quality of life assessment scores	Age at onset (years)		Test sig.	of P
	<25 (n=20)	≥25 (n=40)		
MoCA				
Range.	26.0 – 29.0	23.0 – 29.0	t=2.130*	0.037*
Mean ± SD.	27.40 ± 0.88	26.67 ± 1.38		
EDSS				
Range.	1.0 – 5.50	1.50 – 8.0	U=219.0*	0.004*
Median	1.50	3.0		
MSWDQ-23				
Range.	8.70 – 59.40	11.90 – 68.30	U=156.0*	<0.001*
Median	16.25	23.90		

t: Student t-test U: Mann Whitney test

p: p value for comparing between the two categories

*: Statistically significant at $p \leq 0.05$

Table (6): Relation between number of relapses of MS and different MS quality of life assessment scores (n=60).

MS quality of life assessment scores	Number of relapses		Test sig.	of P
	≤3 (n=38)	>3 (n=22)		
MoCA				
Range.	23.0 – 29.0	23.0 – 27.0	t=3.495*	0.001*

MS quality of life	Number of relapses		Test of P	
Mean ± SD.	27.22 ± 1.17	26.0 ± 1.20		
EDSS				
Range.	1.0 – 6.50	1.50 – 8.0	U=170.0*	<0.001*
Median	2.0	5.0		
MSWDQ-23				
Range.	8.70 – 59.40	16.50 – 68.30	U=151.0*	<0.001*
Median	17.10	42.35		

t: Student t-test U: Mann Whitney test
 p: p value for comparing between the two categories
 *: Statistically significant at $p \leq 0.05$

Table (7): Relation between disease duration and different MS quality of life assessment scores (n=60).

MS quality of life assessment scores	Disease duration (years)		Test of P	
	<5 (n=34)	≥5 (n=26)	sig.	
MoCA				
Range.	23.0 – 29.0	23.0 – 28.0	t=1.617	0.111
Mean ± SD.	27.15 ± 1.31	26.62 ± 1.20		
EDSS				
Range.	1.0 – 6.50	1.50 – 8.0	U=200.5*	<0.001*
Median	2.0	4.25		
MSWDQ-23				
Range.	8.70 – 62.70	16.50 – 68.30	U=216.0*	0.001*
Median	17.40	29.85		

t: Student t-test U: Mann Whitney test
 p: p value for comparing between the three categories
 *: Statistically significant at $p \leq 0.05$

DISCUSSION

Multiple sclerosis (MS) is a central nervous system (CNS) autoimmune disease characterized by inflammatory demyelination, widespread damage, and brain volume loss, which results in neurodegeneration and physical impairment. The majority of MS patients have severe symptoms that lead to a variety of limitations and a disrupted life rhythm. In addition, if there is condition progression, individuals may require support with everyday tasks, which is usually supplied by informal careers such as spouses or other relatives (Multiple Sclerosis International Federation) (MSIF). Due to their medical issues, many MS sufferers have expressed pessimism, unemployment, and retirement [2].

One of the most prevalent causes of neurologic impairment in young people is multiple sclerosis. Because handicapped people require assistance in completing everyday chores and managing prescriptions, disability affects not just the patient but also the entire family. Egypt has the greatest number of MS patients in the Middle East area [1]. So, this study aimed to identify the burden of MS on

patients. In addition, we aimed to assess physical and mental disability in MS patients, to evaluate the effect of MS on work performance and quality of life (QoL) of patients. Our study included sixty patients diagnosed as MS including 18 (30%) males and 42 (70%) females. According to the course of the disease in our MS patients, 49 (81.7%) patients had RRMS, 6 (10%) patients had PPMS, and 5 (8.3%) patients had SPMS.

In the present study, we observed that the mean age of MS onset was (32.80 ± 7.49). This goes in line with the results of North American Research Committee on MS registry, where the age of onset was 31.4 ± 9.7 years [4]. Our results showed that female to male ratio was 2.3:1 which agreed with an Egyptian multicenter registry study of clinical characteristics of patients with MS that enrolled 950 Egyptian patients and confirmed female dominance in MS patients with female to male ratio was 2.57:1[5].

This greater risk of MS in women, according to Voskuhl, is due to particular physiology and hormonal related variables. Furthermore, inactivation of the X chromosome in women

(skewed X chromosome), leading in MS overrepresentation. Environmental variables such as sun exposure and vitamin D supplementation may also affect men and women differently [6]. In our study, the mean disease duration was 5.17 ± 3.91 years. Lufriu and colleagues reported longer disease duration 10.3 ± 9.7 years among MS patients [7].

We found that the mean number of relapses was 3.40 ± 1.58 nearly the same as that observed in the previous registry done in Egypt that was 3.97 ± 3.2 [5]. To assess the clinical disability of MS patients, we have chosen reliable, validated and well accepted clinical scores. First, The Expanded Disability Status Scale (EDSS) which is the most commonly used rating scale to evaluate the clinical status of patients with MS. It has the advantage of being the most widely accepted and familiar measure of disability in MS and it is not particularly difficult or time consuming to perform. The mean EDSS score of our patients was (3.14), nearly similar to the results observed in many Arab countries such as Kingdom of Saudi Arabia (2.5) [8] but was lower when compared with patients in Jordan (3.9) [9].

The examination of the cognitive function of our MS patients revealed that their mean MoCA was 26.92 ± 1.28 . Aksoy and colleagues found that the mean MoCA score in their sample was 21.74 ± 4.48 [10]. We observed that our MS patients with more disability (EDSS more than 3.5) have statistically significant cognitive affection according to MoCA score ($P = 0.001$). These results agreed with Ruano and colleagues. In MS patients, they discovered a link between global cognitive impairment and a higher EDSS. Patients with progressive subtypes were more likely to make errors on orientation questions and serial subtraction than those with RRMS, and the EDSS was a unique predictor of MOCA scores [11]. In our study work performance related to physical, cognitive/psychological, and external barriers dimensions was studied with the MSWDQ-23 and we found that the mean MSWDQ-23 score of our MS patients was 28.81 ± 17.96 with median (IQR) 22.40 (16.25-

39.15), that was slightly lower than that observed by Garcia and colleagues as they reported that median MSWDQ-23 total score was 31.5 (15.2-50.0) [12]. We observed high statistically significant increase in workplace problems according to MSWDQ-23 score in MS patients with more disability (EDSS more than 3.5) ($p < 0.001$), in patients' group with age of MS onset ≥ 25 years old ($P < 0.001$), those with more than three relapses ($P < 0.001$), patients with disease duration equal or more than five years ($P = 0.001$). There was a statistically significant positive correlation with age of patients, age at onset of illness, duration of illness, number of relapses, and number of admissions to hospital.

CONCLUSIONS

Finally, this study demonstrates the substantial impact of MS on patients' QOL, owing to the patients' psychological and physical conditions, as well as the unfavorable influence on work conditions. People with MS and their families face severe financial and social consequences as a result of the disease. MS has a wide range of societal consequences, including interruption of young patients' education and community involvement, in addition to financial expenses to the healthcare system and lost productivity. An improved knowledge of MS patient requirements, including the perspectives of patients, might have a significant influence on quality of life and disease management.

RECOMMENDATIONS

Further studies with larger sample size including different types of MS are needed to detect the burden of MS and its impact on patients' quality of life, also to find ways to alleviate patients and to facilitate the difficulties they face, in the interest of a better QOL for them. We have to encourage patients to keep on doing physical therapy and to be adherent to disease modifying therapy. We also recommend more specialized MS clinics that put into consideration the psychological factors, burden of the disease, multidisciplinary approach, and support groups, which are currently few.

Conflict(s) of interest: None

Financial Disclosures: None

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